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## Life, Death, and Biocultural Literacy

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It is a literary convention that at the moment of death, one may finally come to know oneself. In many of Dickens's novels, for example, you'll find a touching deathbed scene. As the dying character fades away, he or she utters a few summarizing words — or, in the case of Shakespeare, a great deal of them — and those around can wipe away a tear and find some significance in the person's demise. In literature, one's identity, paradoxically, often comes to fruition at the moment of death.

But while Dickens had metaphorical harps and angels to enhance self-revelation at the time of death, we have ventilators, feeding tubes, and defibrillators. Death for us isn't so much a final revelation of identity as a series of decisions preceding a finality. Our sense of identity is much less clear than it was for people in the past. For Dickens and his contemporaries, the division between life and death was fairly knowable. But now, at every step through our life and death, we have to take into account technological innovations that newly define what it means to be human.

As a result of the publicity surrounding the Terri Schiavo case — a legal brawl between her husband and other family members about whether her feeding tube should be removed after she had been in what some doctors had diagnosed as a "persistent vegetative state" for 15 years — many of us are writing living wills. In so doing, we have to think about not only what it means to be a human, but also at what point people cease to have identities.

Liberals might argue that one's identity ceases to exist with the loss of a certain level of consciousness, accompanied by the necessity of mechanical life support, such as a feeding tube and ventilator. The religious right contends that one has an identity as long as one's heart is beating, regardless of one's cognitive function or the need for external life support. Some people see being a "vegetable" as an insult to existence, while others see it as a variety of life. In writing our own living wills, we must attempt to define our identity and to project what our identity would and should be if we were comatose — that is, permanently unconscious and unresponsive; in a persistent vegetative state — that is, awake but unaware; minimally conscious; or severely disabled. By doing that, each of us is wrestling in our small corner of existence with very large questions concerning the point at which identity meets biotechnology.

The problem is that most of us are ill equipped to make those choices because we know so little about the facts of life and death. That is probably one reason why at least a third

of people who make advance directives change their opinions within two years, according to a 2004 Hastings Center report, "The Failure of the Living Will," by Angela Fagerlin, a medical researcher, and Carl E. Schneider, a law professor, both at the University of Michigan. Our college educations provide us with almost no way to sort through such end-of-life decisions. Most of us know very little about biology, don't keep up on recent developments in neurology, and barely know the difference between a coma and persistent vegetative state. We rely on our physicians to tell us about the complexities of medicine, and some of us search the Internet to find out what our doctors won't say. In short, we have to make up and cobble together what we didn't learn in school. There are few if any college-preparatory courses or a single discipline that prepares us to grapple with the questions that are emerging in the postmillennial public sphere.

So when it comes to understanding what makes us human, what defines consciousness and personhood, when life begins and ends, we often have to shoot from the hip. And that can mean we end up shooting ourselves in the foot. When we as a culture have to address issues of life and death — such as whether we should allow stem-cell research or third-trimester abortions, whether we should cause people like Terri Schiavo to die, whether people in Oregon are right to allow physician-assisted suicide — we are often at a loss and inconsistent in our positions.

The public historically has turned to scholars and researchers to inform difficult public debates. But it isn't really clear what part of the academy should be the go-to profession or department. Certainly bioethics seems a logical area of study to resolve contemporary questions of life and death, but few undergraduates are expected to take a required course on those issues, and the field of bioethics itself tends to be fairly specific, dealing mostly with medicine, too often without connecting the ethical issues to a broader vision that includes history and culture.

Philosophy and political theory are rich areas of study for dealing with life-and-death issues, and the writings of John Rawls, Richard Rorty, and John Stuart Mill can help us understand citizens' rights and liberal thought. But we then would have to graft those discussions onto situations that require some medical and scientific knowledge. While a few university programs engage in that kind of synthesis, most of us are doing this work on our own, without a substantial commitment from academe to help us out.

Disability studies is one field that is beginning to pull together several disciplines to address the philosophical, moral, legal, medical, and cultural questions emerging from the intersection of biotechnology and identity. Students of disability studies will be prepared to discuss medical interventions, the use of technology in medicine, the way in which society thinks about the body, and so on. But the problem is that most citizens, because they don't think of themselves as disabled, will not turn to disability experts to help them understand the complex issues highlighted by the Schiavo muddle.

Therefore, that case, which dealt with a severely disabled woman, came down in the popular press to a debate between members of the religious right and the liberal left. But neither side was particularly knowledgeable about the nature of a persistent vegetative

state and whether a feeding tube should be considered a medical intervention (in which case, by a Supreme Court ruling, it could be removed) or simply a form of providing nutrition (in which case it couldn't). Most of the people I talked with thought Schiavo was "brain dead" — an inaccurate term, since her brain was working well enough to keep her alive. Bioethicists were used freely by both sides, but, aside from the openly religious ethicists, the majority followed the bioethics party line that has fostered and encouraged a rather strict notion of autonomy based on the patient's informed consent.

When bioethics began as an academic profession, its goal was to promote a notion of patient autonomy as opposed to the previously unchallenged authority of the medical profession. Therefore most of the bioethicists consulted in the case were in favor of removing Schiavo's feeding tube, since, they maintained, that was the course of action she had wanted, according to her legal guardian.

Bioethicists fear that interventions by religious groups or the government will muck up the principle of patient autonomy. But autonomy is a somewhat limiting principle, despite its obvious utility, if you think of the issue not as what a legal guardian wants, or says a patient wants, but as what or how a society defines "a life worth living." That is, if you thought of Schiavo as a "vegetable," your notion of her autonomy would have pointed to removal of the feeding tube. But if you thought of her as a severely disabled woman, the notion of autonomy would have become more ambiguous. That is the position that most people in disability studies took, and so they supported leaving the feeding tube in place.

The brouhaha raised the question of how we understand identity in an age that is increasingly "biocultural," to use a term emerging recently. A biocultural approach combines the disciplines of science, technology, medicine, and the humanities. This nascent discipline — which I have been calling "biocultures" — is often practiced by graduate students or professors in departments of history, gender and women's studies, criminal justice, medical education, history, science studies, anthropology, literature, and cultural studies. Programs such as those at the University of California at Berkeley, Duke, Harvard, the University of Illinois at Chicago, the University of Michigan, and Pennsylvania State University bring together issues concerning the body, identity, history, and culture. The trend is important because it is crucial not just for scholars in the humanities to know the impact that science has on culture and the body, but also for scientists, limited by funds earmarked for increasingly narrow research topics, to think more broadly about the political, cultural, and social implications of what they do.

Take the prickly subject of abortion. Most people have strong feelings about it, but few have the biocultural literacy necessary to understand the complexity of the factors involved. And those with the technical knowledge often lack understanding of the cultural and historical contexts in which abortion needs to be considered. A biocultural approach to questions surrounding abortion would encompass the latest scientific facts about reproduction, conception, implantation, pregnancy, and so on. But it would also consider the cultural, moral, and religious contexts that surround the medical issues. Further, a biocultural approach would take into account the social and political history of the debates themselves, as well as related ethical and philosophical issues, such as

infanticide, prenatal testing, developing-world uses of abortion, animal rights, and the death penalty. In other words, just as you can't fully discuss Shakespeare without having a certain level of cultural literacy, you can't fully discuss issues like abortion without biocultural literacy.

A biocultural approach to Terri Schiavo — and, by extension, the 10,000 or more people in persistent vegetative states throughout the country — would have included a discussion of whether she, even in her attenuated state, had an identity. Was she a human being? A disabled woman? A *homo sacer* (the philosopher Giorgio Agamben's notion of someone who is alive but can be killed without fear of punishment, like Holocaust victims or ostracized ancient Greeks)? What exactly is the status of people who are connected to life-support machinery, newborns with hopeless fatal illnesses, fetuses, fertilized embryos, stem cells, patients in the last stages of Alzheimer's disease, and those dying of cancer or ALS?

These are perhaps the most crucial identities of our times — what the science historian and disability-studies scholar Susan Squier calls "liminal lives": those that test our ability to define identity and life itself. We will be seeing a huge public debate in forthcoming months as the Supreme Court considers *Gonzales v. Oregon*, deciding if terminal patients in Oregon can have physicians assist them with suicide. Do dying people have an identity that is different from that of ordinary citizens who cannot ask physicians for lethal drugs? Stem-cell research and cloning will continue to be enormous issues. And, of course, abortion remains one of the major splitting points between Democrats and Republicans.

How can colleges, universities, and the disciplines inform the public about cutting-edge biocultural issues? How can our students and faculty members be educated so that they can think consistently and logically about these questions, so that their feelings can be supported with facts? The academy needs a major initiative to provide education on these issues that communicates the complexities and nuances involved. But if we are not careful, confusion rather than clarity will result.

First, it is imperative that we communicate facts rather than opinions. When we talk about abortion, for example, we need to know when implantation takes place, when the embryo's nervous system develops and begins to feel pain, and in what week viability occurs (when the fetus can survive outside the womb). When we discuss the history of religious attitudes toward abortion, we need to know, for example, when the Roman Catholic Church changed its definition of the beginning of life from the "quickening" of the fetus to the moment of conception.

Second, we must be consistent about definitions and willing to challenge inconsistent positions. For example, the right historically has supported individual and state autonomy and therefore has generally opposed federal intervention in individual or states' rights. But in recent years the right, particularly the religious right, has sought federal intervention against individual autonomy in issues concerning the right to life and personal choice — for example, abortion and gay marriage. For the right in general and the religious right in particular, one's identity is based on the sanctity of life, extending to

patients in comas or vegetative states, fetuses in the womb, and byproducts of fertilization such as stem cells and unused embryos. But any logician could inform the debate by pointing out the inconsistency between those positions and support for the death penalty, war, and even the eating of animals.

The left favors autonomy in regard to the body, resisting the idea that the state should dictate how and what we do with our bodies. So it favors abortion, gay marriage, and freedom of sexual choice between consenting adults. It hits a wall, though, in the area of liminal lives. Here it is quick to say that people in vegetative states don't really have identities and therefore are not autonomous. While the left's support of removing Schiavo's feeding tube appeared to support her autonomy (by assuming that she would not have wanted to be a vegetable), it actually was saying that we should assume that people who are disabled enough to be unconscious no longer have identities. According to that view, those people — paradoxically — no longer have the ability to have chosen to stay alive. The left's position on abortion supports the right of parents to abort fetuses with disabilities, while it objects to the abortion of female fetuses in other countries. In addition, the left supports late-term abortions — although presumably it opposes infanticide — even though, because of biotechnical advances, the line between inside the womb and outside the womb has become somewhat arbitrary and largely a matter of conjecture. Now that a third-term fetus can easily be removed from the womb and survive, its existence inside or outside the womb is mostly determined by medical practice or even parental choice.

Finally, in thinking about these issues, academics must be leery of the pull of identity politics, which condition many of our responses in the university. Those on the right think they know the answers to questions about identity; those on the left think they do as well, even if neither position is internally coherent. Another way of saying this is that we have to state openly where our theories begin to fall down, where we become incoherent, where our personal biases and identity politics muddy the waters.

One example, which no doubt will upset many of my disability-studies colleagues, illustrates my point. Disability studies is fundamentally based on, among other things, the idea that people with disabilities should have autonomy over their own lives. The independent-living movement and much disability legislation stress that barriers to active participation and self-determination should be removed. Better to live at home with personal assistants, to work without discrimination, to navigate the streets without barriers, to communicate by all means, and to use adapted media and technology to function as fully as possible than to be cared for in facilities, be confined to a home, and be limited by "ableist" environments without ramps or curb cuts, accessible Web sites, or classrooms with real-time captioning. Yet disability scholars and activists also believe that autonomous identity is tempered by recognition that we are all interdependent, that the model of the free and autonomous individual is a bit of a myth, and that the demand that we all be "normal" is a burdensome and limiting ideal.

But in the Schiavo case and in the Supreme Court hearing of challenges to the Oregon law permitting physician-assisted suicide, many disability scholars have found

themselves on the same side as the right-to-life movement in opposing the removal of Schiavo's feeding tube and physician-assisted suicide. It is striking that a movement with roots in liberal-to-left feminism, the fight for civil rights, and the demand by progressive, disabled Vietnam veterans for proper treatment now appears to the public to be aligned with the religious right and social conservatives on those issues.

Those who support physician-assisted suicide argue that individuals with all their mental capacities have the right to end their lives before they become incapacitated. It is their right as autonomous individuals. Many disability advocates, on the other hand, claim that all people who are dying are, in fact, disabled, and that their identity as disabled individuals trumps their identity as autonomous beings. The faulty syllogism goes that dying people are disabled, and in an ableist society they naturally will be pressured to kill themselves; ergo disabled people are being put to death through physician-assisted suicide. Further, dying people (read "newly disabled") will ask for physician-assisted suicide specifically because they do not wish to be disabled — to lose their sight, hearing, voice, mobility, and so on.

There are at least two flaws in that argument. First, it is hard to shoehorn someone dying of cancer, for example, into the category of chronic disability. The aim of making it possible for disabled people to live full lives with their impairments and of ensuring a free and accessible society has little to do with someone who will be dead in six months (the requirement for receiving physician-assisted suicide in Oregon). Why should people have to accept disability status when they will be dead within a few months? Second, according to statistics provided by Oregon, most people seeking physician-assisted suicide are end-stage cancer patients who, by and large, are educated, middle class, and informed. While it is true that many seek physician-assisted suicide because they fear losing their abilities and their autonomy, they no doubt have the independent judgment to make that decision.

It seems illogical for some disability advocates to try to prevent dying people from choosing a humane way of ending their lives (as opposed to shooting themselves or wrapping a plastic bag around their heads) because those advocates see suicide as a critique of the disability perspective.

The activist origin of the disability movement laid down certain positions — notably opposition to euthanasia and physician-assisted suicide — that have become the rule and therefore difficult to challenge. Indeed, a long history of abuse against people with disabilities, culminating in eugenics and discrimination, supports those positions. But there are important distinctions between physician-assisted suicide and euthanasia: The former allows patients to take by themselves a lethal overdose of a drug prescribed by a physician for that purpose; the latter requires that someone else, a physician, be the murderer. One could logically support suicide as a self-determining act while opposing murder. Yet the religious right lumps physician-assisted suicide, euthanasia, and abortion together, and so do many in the disability community. A more nuanced approach, a biocultural one, would make distinctions.

In the end, we are all poorly served by an academic community that does not promote biocultural literacy. As this century moves on, many issues the public needs to discuss will increasingly be tied to biotechnological advances that challenge our definitions of what it means to be human. We will need all the resources that we can command to come up with consistent, logical, and culturally relevant ways of conceiving of and bidding farewell to our bodies, ourselves.

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